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DEMOGRAPHIC AND SOCIAL STATISTICS

Report on demographic, social and migration statistics

Report of the Secretary-General

SUMMARY

The addendum contains further information on gender statistics and on impairment, disability and handicap statistics, including the recommendations of the United Nations Expert Group Meeting on the Development of Impairment, Disability and Handicap Statistics (Voorburg, the Netherlands, 7-11 November 1994) (annex).

Points for discussion are included at the end of each chapter (paras. 6 and 17).

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I. GENDER STATISTICS

1. The primary objectives of the gender statistics programme of the Statistical Division of the United Nations Secretariat (UNSTAT) are to effect the long-term improvements in statistical concepts, methods and data collection that are needed to provide unbiased quantitative monitoring and analysis of the situation of women and of equality and equal opportunity between men and women. In 1994-1995, the main specific activities and objectives of the programme are:

(a) The publication of the second edition of The World's Women: Trends and Statistics as a main official background document for the Fourth World Conference on Women (to be held in Beijing, 4-15 September 1995). The publication is being prepared with funding from the Department for Public Information and the Division for Advancement of Women of the United Nations Secretariat, the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Development Fund for Women (UNIFEM), the United Nations Population Fund (UNFPA), the World Food Programme (WFP), the International Research and Training Institute for the Advancement of Women (INSTRAW), and the United Nations Educational, Scientific and Cultural Organization (UNESCO);

(b) The dissemination and promotion of the second edition of The World's Women as a United Nations publication with a very substantial global audience and proven sales potential. As of November 1994, about 22,000 copies of the first edition 1/ had been sold in all languages and about 4,000 complementary copies had been distributed to official Government users;

(c) The dissemination and promotion of the newly updated Women's Indicators and Statistics Database (Wistat) on CD-ROM and diskettes and on public-access on-line networks. The development of Wistat has been supported by UNFPA; it is now widely used and recognized as by far the most comprehensive and authoritative international data source available for gender statistics, research and analysis at the national, regional and international levels;

(d) The publication of a technical guide for the preparation of national gender statistics reports, and the provision of technical support to national and subregional training programmes in the field by assisting in training workshops for the development of national gender statistics publications and programmes, as well as collaborating with other agencies and institutions in the development of their training materials;

(e) The provision of statistical information for the Fourth World Conference on Women in its consideration of gender statistics issues in the draft platform for action, including participating in developing the draft platform by working with the Division for the Advancement of Women, working with drafting groups at meetings of the Preparatory Committee for the Conference and working with expert group meetings, as well as working with non-governmental organizations and national representatives on an ad hoc basis. The issues to be addressed include how to make further improvements in statistical concepts and methods; national, regional and international data collection, dissemination and analysis programmes; the measurement and valuation of unpaid work; the

development of satellite accounts to national accounts on women's economic contribution; 2/ measurement and data collection in the area of women's economic contribution to the informal sector; and the measurement and monitoring of women's rights;

(f) The coordination of gender statistics in the global statistical system by developing coordinated and integrated statistical outputs to avoid duplicate and inconsistent data-collection and compilation activities, working with a wide range of users in order to make those procedures and data available in formats that are easy to use and widely available.

2. Extensive research, data compilation and preliminary analysis for the preparation of the second edition of The World's Women: Trends and Statistics were largely completed in mid-1994. Findings were reviewed with the sponsoring agencies in the second half of 1994 and final publication in all languages is scheduled for mid-1995. The new edition will contain chapters on population, families and households; population and environment; health; education science and media; and work and power. Its presentation and analysis have been carefully reviewed to take into account the conclusions and recommendations of the International Conference on Population and Development (see A/CONF.171/13 and Add.1). The second edition will highlight new and innovative statistics on such subjects as women and national accounting, women in science and the media, and women in positions of power.

3. The second comprehensive update of the Women's Indicators and Statistics Database (Wistat), supported by UNFPA, was completed in August 1994 in close cooperation with the regional commissions. Wistat is the main data source for The World's Women and is being issued on diskettes and CD-ROM for independent research and analysis at the national, regional and international levels.

4. The manual in preparation by UNSTAT for national use on how to compile and organize statistics on gender issues and how to present tables and charts and write up quantitative analysis will be completed and issued in draft form in fall 1994; it will be published in final form in 1995. Work on the manual is supported by the Joint Consultative Group on Policy (JCGP), a coordinating body comprising UNICEF, UNDP, UNIFEM, UNFPA, WFP and the International Fund for Agricultural Development (IFAD). The project is being undertaken with JCGP in gender statistics in response to the impact of The World's Women and the need expressed by many countries for help in producing similar national gender statistics reports, in particular in the light of the Fourth World Conference on Women.

5. Three workshops on gender statistics using materials prepared for the manual have been held (Botswana, August 1993, sponsored by Swedish International Development Agency (SIDA); Morocco, 13-17 December 1993, sponsored by INSTRAW; and Thailand, January 1994, sponsored by SIDA and UNIFEM). The same project is also supporting initiatives to develop publications similar to The World's Women for two countries at the national level as well as for the Economic and Social Commission for Western Asia (ESCWA) region as a whole. In addition, UNSTAT is assisting several countries in developing gender statistics reports in connection with ongoing statistical projects, for example in Kenya and Bangladesh.

6. The Statistical Commission may wish to:

(a) Take note of the progress made in the preparation of statistical documentation for the Fourth World Conference on Women, including the preparation of the second edition of The World's Women: Trends and Statistics;

(b) Comment on the feasibility and desirability of adapting the collaborative and analytical approach that was adopted in the preparation of The World's Women to other national and international statistical publications in various social fields;

(c) Comment on the desirability and use of a classification of activities for use in time-use statistics, in particular for measuring the contributions of women and men to the economy and to work. The Commission may also wish to consider the UNSTAT proposal to prepare a draft trial classification in the field as a basis for further research and special studies.

II. IMPAIRMENT, DISABILITY AND HANDICAP STATISTICS

7. UNSTAT work on the development of impairment, disability, and handicap (IDH) statistics has progressed in two major areas:

(a) The design of statistical methodology and standards for data collection and the development of global indicators;

(b) The production of statistics and indicators of disability.

8. As to the former, UNSTAT convened the United Nations Expert Group Meeting on the Development of Impairment, Disability and Handicap Statistics (Voorburg, the Netherlands, 7-11 November 1994), which was hosted by the Central Bureau of Statistics of the Netherlands; the purpose of the Meeting was to (a) review existing disability data-collection methods and standards, and (b) prepare, based on the outcome of that review, a guiding set of principles for use in censuses, surveys and registration systems. At that Meeting, the Expert Group reviewed a draft of the proposed handbook on census and survey methods for the development of IDH statistics. The Expert Group acknowledged the increase in the demand for national and international IDH statistics that had resulted from the growing commitment of Governments around the world to the rights, welfare and health of persons who experience IDH. The Expert Group felt that, since government policies and programmes on IDH were currently proliferating, there was an even greater need for the leadership and guidance of UNSTAT in the context of increased attention to social statistics. Because IDH statistics was a newly emerging area of statistical development, the Expert Group requested that its recommendations, which are contained in the annex to the present report, be submitted to the Statistical Commission for review at its next session.

9. The Expert Group paid special attention to the use by countries of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) of the World Health Organization (WHO) as well as the WHO revision process. For that reason, the Expert Group Meeting had been planned to precede WHO's Second

International Meeting on the Revision of the International Classification of Impairments, Disabilities and Handicaps (Voorburg, the Netherlands, 14-18 November 1994).

10. In anticipation of the Expert Group Meeting, UNSTAT and the North America Collaborating Centre of the United States National Center for Health Statistics had jointly organized an international meeting on the theme "Scientific review of applications: International Classification of Impairments, Disabilities and Handicaps (St. Michaels, United States of America, 31 May-3 June 1994). The purpose of that meeting was to discuss the proposed handbook on census and survey methods for the development of IDH statistics before its review by the Expert Group.

11. A set of global indicators were proposed in the 1993 framework for the Third Monitoring of Progress towards Health for All (HFA) to be carried out at the national level by all Member States, including a disability-related indicator jointly developed by WHO and UNSTAT: "The number of people identified as having one of the following types of disabilities: difficulty seeing, difficulty hearing, difficulty speaking, difficulty moving, difficulty learning/ comprehending/remembering, or other (please specify)" (see WHO/HST/GSP/93.3). A similar indicator has been developed by UNICEF and WHO in collaboration with UNSTAT for use in the assessment of progress towards the aims of the World Summit for Children; it is contained in a UNICEF/WHO document entitled "Joint WHO/UNICEF recommended indicators for monitoring health goals of the World Summit for Children" (see CS/PROG/IL/93-072, recommendation No. 8), and is recommended by WHO and UNICEF for National Monitoring and programme management and international reporting.

12. As to the actual production of statistics and indicators, dissemination and use of the United Nations Disability Statistics Database (DISTAT) has continued. In 1994, consultants to UNSTAT prepared a report entitled "A human development agenda for disability: statistical considerations", which suggests possible approaches to including IDH in the monitoring of human development outcomes; the report was based on DISTAT and its preparation was supported by the Swedish Organization of Handicapped International Aid Foundation (SHIA).

13. A special article entitled "Disability statistics in studies of ageing" was published in the Demographic Yearbook-Special Issue: Population Ageing and the Situation of Elderly Persons; 3/ the article presents age and sex-specific disability data for 57 countries and discusses their implications for policy formulation and programme planning, and its preparation was supported by UNFPA.

14. As a contribution to the International Year of the Family, statistics on the disabled for 87 countries were published in the Statistical Chart on World Families, 4/ supported by the Trust Fund for the International Year of the Family.

15. A report has been prepared by UNSTAT and WHO for the Fifth Economic Commission for Europe (ECE)/WHO Joint Meeting on Health Statistics, Conference of European Statisticians, entitled "The ICIDH and the development of disability statistics" (CES/AC.36/51) (EURO/ICP/HST/157/51). In addition, the report of the International Workshop on the Development and Dissemination of Statistics on

Persons with Disabilities is now available in English and French; 5/ the report summarizes the conclusions of a meeting organized by Statistics Canada and UNSTAT (Ottawa, 13-16 October 1992).

16. UNSTAT has prepared, in collaboration with WHO, a draft statistical training manual for the development of disability statistics, prepared especially for the use of managers and programme planners in the production of national disability statistics through surveys, censuses and registration systems; the manual is to be published by the United Nations in 1994, with the support of SIDA.

17. The Commission may wish to assign priorities to the recommendations of the Expert Group and to indicate the role of UNSTAT in implementing them.

Notes

1/ The World's Women: Trends and Statistics, Statistical Papers, Series K, No. 8 (United Nations publication, Sales No. E.90.XVII.3.

2/ See Report of the World Conference to Review and Appraise the Achievements of the United Nations Decade for Women: Equality, Development and Peace, (United Nations publication, Sales No. E.85.IV.10), chap. IA, para. 120, and Official Records of the Economic and Social Council, 1989, Supplement No. 3 (E/1989/21), para. 141.

3/ United Nations publication, Sales No. E.92.XIII.9.

4/ Statistical Papers, Series Y, No. 7 (United Nations publication, Sales No. E/93.XVII.9).

5/ Issued by Statistics Canada (Ottawa, 1993).

Annex

RECOMMENDATIONS OF THE UNITED NATIONS EXPERT GROUP MEETING ON THE DEVELOPMENT OF IMPAIRMENT, DISABILITY AND HANDICAP STATISTICS

(Voorburg, the Netherlands, 7-11 November 1994)

A. General recommendations

1. In the light of the World Programme of Action concerning Disabled Persons, which was adopted by the General Assembly in its resolution 37/52 of 3 December 1982, and of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which were adopted by the General Assembly in its resolution 48/96 of 20 December 1993, it is increasingly recognized that statistics on impairment, disability and handicap (IDH) should support policy-related issues. IDH data often have multiple purposes: national surveillance; the monitoring of opportunities for work; education; health care; independent living; the assessment of social security systems; the determination of disability benefits; the establishment of priorities for prevention programmes for primary health care; maternal and child health; and accident prevention. All those areas require IDH statistics.

2. The United Nations Expert Group Meeting on the Development of Impairment, Disability and Handicap Statistics recommends that a set of standard instruments for the survey measurement of IDH be established by 2001, five years after the publication of the handbook on census and survey methods for the development of IDH statistics that has been reviewed by the Expert Group. In order to achieve that goal, there should be a continuous procedure that provides for the formulation of new common instruments, the testing and evaluation of such new instruments, and agreement on and revision of standards. The process of achieving common standards should be effected in three stages: (a) the formulation of the recommended instruments for promotion and testing in interested countries; (b) the testing of those instruments and evaluation of experience in their use; and (c) the formulation of standard instruments on that basis. Criteria for testing and evaluation should be established, including testing in a minimum number of countries in different continents by means of representative surveys and based on agreement regarding the usefulness of results for policy and planning. In designing common standards, the Expert Group recommends that, as far as possible, a minimum set of measures be established for every standard instrument. The Expert Group also recommends that a minimum set of IDH tabulation items and core data tables be prepared by UNSTAT, and that those items be disseminated for review, further discussion and, ultimately, for recommended use among countries for developing and disseminating IDH statistics.

3. The Expert Group agrees that it is vitally important for all countries to collect information on the IDH status of their populations. Countries that have never surveyed their populations with respect to IDH or have not done so recently should consider including IDH questions in their next census round or initiating an IDH survey. The frequency of data collection using surveys can range from ad hoc or one-time efforts to continuing efforts (always in the

field), depending on how often data are needed for basic population and demographic information, the planning of services, and general health and social policy.

4. The census questionnaire used for complete coverage of the population should not be overloaded with detailed specialized questions on impairments, disabilities, handicaps or any other topic. The Expert Group recommends that, if the objective of including IDH items in a census is to estimate prevalence rates of IDH, a comprehensive short list of IDH items should be used, and work should be initiated to develop such comprehensive short lists and to carry out validity studies of the proposed lists. The lists should be applicable to children (perhaps above a threshold age), the working-age population and the elderly. A broad IDH question may be included in censuses in order to identify the potential for a more detailed follow-up survey. Such broad and non-specific screening questions should be designed to have a high degree of sensitivity but may have low specificity and should not be used to estimate IDH prevalence; the follow-up survey can contain a detailed set of questions to identify the various types of IDH. The question used in some censuses for including IDH as a reason for being economically inactive is not useful for estimating prevalence rates for the total population.

5. Countries that have collected data on IDH should be encouraged to process and disseminate their results. National statistical workshops and seminars should be used to increase the awareness of Government offices and policy makers concerning the usefulness of IDH statistics for policy formulation, programme planning and implementation.

6. In survey planning, the development of questionnaires and the consideration of ethical issues and language and fielding strategies, as well as in planning public relations and education campaigns about survey goals, it is essential to consult organizations of people with disabilities and other interested organizations that deal with the issue of IDH. Persons with disabilities, the organizations that represent them and proxy informants, such as family members and care providers, should be asked to describe their experiences with IDH so that those experiences may be taken into consideration in the planning of survey questions.

B. The International Classification of Impairments, Disabilities, and Handicaps

7. In order to develop a common framework, those undertaking censuses and surveys are encouraged to utilize the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a standard reference; they are also encouraged to use the concepts contained in the World Programme of Action concerning Disabled Persons, specifically those relating to the goals of prevention, rehabilitation and equal opportunity. The common framework represented by the combined use of ICIDH and the World Programme of Action provides a conceptual link between policies for reducing impairments, disabilities and handicaps and the three major goals of prevention, rehabilitation and equalization of opportunity, thus permitting a broad spectrum of IDH-specific policy and research topics to be addressed.

8. There is a parallel and dependent relationship between the international decisions reached on the development of statistical guidelines for the study of impairments, disabilities and handicaps (referred to hereinafter as IDH statistics), on the one hand, and the further development and use of ICIDH on the other. The Expert Group notes with satisfaction the collaboration and coordination undertaken by UNSTAT and WHO, which has encouraged agreement among census and survey planners and the groups working on the ICIDH revision; the Expert Group recommends that that coordination continue. Any conclusions and recommendations concerning ICIDH concepts and classifications will be subject to the changes and general agreements made during the ICIDH revision process.

9. The Expert Group also recommends the development of guidelines for the measurement of severity; short-lists for use in coding and presenting national census and survey data on IDH; and a general agreement on the development and use of simple, comparable and reliable indicators and survey instruments of IDH for national and international monitoring.

10. No agreement has been reached on a general term to describe either the field of IDH statistics or the population of persons who have been screened into surveys either because they have an impairment or disability or because they experience some form of handicap. The Expert Group recommends that that question revert to the WHO/ICIDH revision process, which should decide on a general term for the IDH field of statistics. Until such a decision is made, terms employed should remain specific to particular impairments, disabilities and handicaps.

C. Data-collection methods: making use of national surveys

11. As a cost-effective way of developing social and health statistics on IDH, ongoing or planned demographic, household and health surveys should include impairment, disability, or handicap instruments at regular intervals.

12. Panel surveys also offer a valuable opportunity to obtain information on transition rates between IDH states, in particular the incidence of disability and the rate of recovery from disability. Such information is important for studying the dynamics of IDH in a population (eg., using multi-state life-table techniques) and for the planning of services. The time interval between survey rounds should be larger than the minimum duration of IDH but as short as possible; one or two years would be optimal.

13. In the context of increasing activities at the international and supranational levels on public health issues, countries should move towards cooperation on surveys on IDH that are already in the planning stages.

D. Testing the validity and reliability of results

14. Substantial research on the evaluation of findings, including studies on the validity and reliability of results, has been carried out by national statistical offices and other bodies. The Expert Group requests UNSTAT to explore possible mechanisms for facilitating the wider dissemination of those

reports; it also recommends that UNSTAT prepare a concise report to consolidate the findings of such evaluation studies and that that report be made available to statistical offices and other interested organizations.

15. The Expert Group also recommends that further research be conducted to examine whether the activities of daily living/instrumental activities of daily living (ADL/IADL) instruments, such as those used by the Organisation for Economic Cooperation and Development (OECD), provide measures related more to disabilities or more to handicaps; the question has implications for the classification of ADL/IADL-free life expectancy and for international comparisons of health expectancies derived from ADL/IADL measures.

E. Technical aids/assistive devices

16. The Expert Group requests that increased attention be given by countries to the collection and presentation of data on special auxiliary devices for the reduction of disabilities and handicaps, and that countries use the newly devised Technical Aids for Disabled Persons Classification (ISO 9999). The standardization of technical aids in surveys should be set at a level of generalization that allows countries to specify technology in a way appropriate to its availability, at a minimum of the chapter levels of the International Standards Organization (ISO) standards. Tabulations should be provided showing the use of such devices by specific IDH groups, age and sex. Emphasis should also be placed on the production of standardized tables showing the need for those devices, and on technical products that are generally available and useful in the reduction of disabilities and/or handicaps included in ISO 9999. After 1995, the revised version of ISO 9999 will be available from ISO in Geneva in English, French, German, the Nordic Languages and Dutch.

F. Cause of impairment or disability

17. The Expert Group welcomes the WHO initiatives to establish short lists of causes and underlying conditions for IDH for the use of standard instruments in censuses and surveys, which were provided by WHO in an information note (ESA/STAT/CA.47/INF.6). Those lists and the underlying conditions provided by WHO should be further elaborated by WHO and UNSTAT in consultation with relevant experts and organizations, with particular emphasis on the measurement of co-morbidity. Such lists are particularly useful for providing a common understanding of programme planning in the area of prevention, for IDH surveillance and for linking disease monitoring with IDH issues.

18. In their definition of IDH states, questionnaire instruments should specify a minimum duration that an IDH has lasted or is expected to last. Unless there are specific reasons for choosing another threshold, it is recommended that the minimum duration or expected duration of six months be used; this period is long enough to exclude periods of short-term disability due to acute illness or external cause but short enough to include all disability episodes that last a considerable amount of time. An IDH question should thus include the qualification that the IDH has lasted or is expected to last for six months. Some questionnaire modules specify a minimum duration for the underlying health

condition rather than the IDH state. The Expert Group recommends that, where possible, the minimum duration should relate to the IDH state in order to achieve the maximum comparability of resulting statistics.

G. Data dissemination

19. Statistical offices are encouraged to provide micro-data files on IDH for use by others, protected against identification and according to national regulations. Special requests for additional ad hoc tabulations should be responded to rapidly and at low cost. A capacity to provide such services should be maintained even long after a survey has been conducted. There is a need for UNSTAT or another research organization to take responsibility for storing public-use micro-data files for international comparative analyses, while giving appropriate consideration to licensing restrictions.

20. IDH statistical reports and publications should be provided for people with IDH in accessible formats, such as large-type; Braille; audio formats, including audiovisual cassettes; ASCII computer disks; and special computer programmes and interfaces for people with intellectual impairments.

21. Questionnaires in their original language should be included in survey reports, with an explanation showing how the variables used to describe IDH are derived from survey questions; a correspondence table showing how variables relate to ICIDH should also be included.

22. Standardized descriptions of IDH data-collection procedures should continue to be produced in DISTAT. Consideration should be given, on a trial basis, to providing statistical offices with standard forms for preparing descriptions of their survey work, for inclusion in DISTAT. Standard forms should request details on definitions and concepts used, research designs, reasons for conducting the survey and so on.

23. The Expert Group recognizes the importance of the recent development of population-based indicators on the prevalence of broad groups of disabilities disaggregated by age-group and by sex, as recommended for use in WHO Health For All monitoring and in the UNICEF/WHO monitoring of health goals of the World Summit for Children. The statistical divisions of the regional commissions and the regional offices of WHO are asked to assist countries in developing and applying such indicators as a baseline source of information on IDH.

24. The international community and Governments are giving significant and increased attention to the development of global IDH indicators, the use of which requires coordination and monitoring by the United Nations system. All indicators should be presented as value-free as possible and their wording should be carefully considered to avoid erroneously implying that people who experience IDH are in any way inferior.

25. Disability-free life expectancy (DFLE) and IDH life expectancy estimates should be implemented as core indicators in health statistics. The sources of age-specific impairment, disability, and handicap rates used in the calculation

of DFLE and IDH life expectancy should be clearly explained using ICIDH terminology.

H. Future work

26. The Group of Experts strongly recommends that UNSTAT continue its work on IDH statistics, including its work on DISTAT and the development of international standards and its work in furthering international comparison studies and research. Because Governments around the world have demonstrated a growing commitment to the rights, welfare and health of persons with IDH, there is a growing demand for national and international disability statistics. With commendable foresight, UNSTAT has anticipated that demand by initiating DISTAT and beginning to develop standards for national and international IDH statistics. UNSTAT has provided leadership and guidance to facilitate the development of national IDH statistics. Since national government policies and programmes on IDH are currently proliferating, there is an even greater need for the leadership and guidance of UNSTAT in the context of increased attention to social statistics.

27. In recognition of that need, the Group of Experts agrees that its individual members will inform their respective Governments of UNSTAT contributions to national and international IDH statistics, and will recommend that their Governments support the continuation of the IDH activities of UNSTAT. In particular, the Group of Experts recommends that UNSTAT continue to dedicate a core staff of professionals and support staff to its IDH activities.

28. The Expert Group requests that the preceding recommendations be submitted to the Statistical Commission at its next session. The Expert Group also recommends that the draft handbook on census and survey methods for the development of IDH statistics that was reviewed by the Expert Group be submitted for publication by the United Nations in all its official languages in 1995, taking into consideration the revisions made by the Expert Group, for use by statistical offices and research organizations as principles and guidelines for IDH statistical work in the holding of censuses and household surveys and the compilation of administrative registries.